

Cerebral palsy in children and young people

Quality standard

Published: 10 October 2017

www.nice.org.uk/guidance/qs162

Contents

Quality statements	5
Quality statement 1: Follow-up for children with major risk factors for cerebral palsy	6
Quality statement.....	6
Rationale	6
Quality measures.....	6
What the quality statement means for different audiences.....	7
Source guidance.....	8
Definitions of terms used in this quality statement	8
Quality statement 2: Referral for children with delayed motor milestones.....	10
Quality statement.....	10
Rationale	10
Quality measures.....	10
What the quality statement means for different audiences.....	11
Source guidance.....	11
Definitions of terms used in this quality statement	12
Quality statement 3: Information for parents and carers of children and young people with cerebral palsy	14
Quality statement.....	14
Rationale	14
Quality measures.....	14
What the quality statement means for different audiences.....	15
Source guidance.....	16
Definition of terms used in this quality statement	16
Equality and diversity considerations	16
Quality statement 4: Personal folders for children and young people with cerebral palsy .	18
Quality statement.....	18
Rationale	18

Quality measures.....	18
What the quality statement means for different audiences.....	19
Source guidance.....	20
Definition of terms used in this quality statement	20
Equality and diversity considerations	21
About this quality standard	22
Improving outcomes	23
Resource impact.....	23
Diversity, equality and language.....	23

This standard is based on NG62.

This standard should be read in conjunction with QS135, QS46, QS19, QS169 and QS191.

Quality statements

Statement 1 Children with any major risk factor for cerebral palsy have enhanced clinical and developmental follow-up from birth to 2 years.

Statement 2 Children with delayed motor milestones are referred to a child development service.

Statement 3 Parents and carers of children and young people with cerebral palsy are given information about the diagnosis and management of cerebral palsy.

Statement 4 Children and young people with cerebral palsy have a personal folder to help them make decisions about how their condition is managed.

Other quality standards that should be considered when commissioning or providing cerebral palsy services for children and young people include:

- Preterm labour and birth. NICE quality standard 135
- Multiple pregnancy: twin and triplet pregnancies. NICE quality standard 46
- Meningitis (bacterial) and meningococcal septicaemia in children and young people. NICE quality standard 19

A full list of NICE quality standards is available from the quality standards topic library.

Quality statement 1: Follow-up for children with major risk factors for cerebral palsy

Quality statement

Children with any major risk factor for cerebral palsy have enhanced clinical and developmental follow-up from birth to 2 years.

Rationale

The signs of cerebral palsy might not be apparent at birth. Following up children with any major risk factor for cerebral palsy for the first 2 years of life will help to identify and diagnose cerebral palsy as early as possible. Early diagnosis can guide interventions, inform prognosis and let family members know what to expect.

Quality measures

Structure

Evidence of local arrangements to provide enhanced clinical and developmental follow-up from birth to 2 years for children with any major risk factor for cerebral palsy.

Data source: Local data collection, for example, service protocols.

Process

a) Proportion of children with any major risk factor for cerebral palsy attending a routine appointment up to 3 months of age who had movement and development checked.

Numerator – the number in the denominator who had movement and development checked.

Denominator – the number of children with any major risk factor for cerebral palsy attending a routine appointment up to 3 months of age.

Data source: Local data collection, such as the Royal College of Paediatrics and Child Health personal child health record ('red book').

b) Proportion of children with any major risk factor for cerebral palsy and older than 3 months who have a planned schedule of developmental follow-ups.

Numerator – the number in the denominator who have a planned schedule of developmental follow-ups.

Denominator – the number of children with any major risk factor for cerebral palsy and older than 3 months.

Data source: Local data collection, such as the Royal College of Paediatrics and Child Health personal child health record ('red book').

Outcome

Number of children and young people with cerebral palsy who were diagnosed by age 2 years.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (such as secondary care services) work together to ensure the provision of enhanced clinical and developmental follow-up for children from birth to 2 years (corrected for gestational age) who have any major risk factor for cerebral palsy.

Healthcare professionals (such as midwives and neonatologists) identify major risk factors for cerebral palsy and refer children who have a risk factor for cerebral palsy for enhanced clinical and developmental follow-up from birth to 2 years (corrected for gestational age).

Commissioners (such as clinical commissioning groups) ensure that they commission services that support children with any major risk factor for cerebral palsy by providing enhanced clinical and developmental follow-up from birth to 2 years.

Babies who have problems that might cause cerebral palsy have their movement and development closely checked until they are 2 years old, because cerebral palsy is not always obvious at birth. Some common causes of cerebral palsy are problems in the way the baby's brain develops before birth, an infection in the baby before or shortly after birth, or a difficult or early (preterm) birth.

Source guidance

Cerebral palsy in under 25s: assessment and management. NICE guideline NG62 (2017), recommendations 1.1.2 and 1.3.1

Definitions of terms used in this quality statement

Major risk factors for developing cerebral palsy

The following are major risk factors for developing cerebral palsy:

- birth before 28 weeks
- neonatal encephalopathy
- neonatal sepsis (particularly with a birth weight below 1.5 kg).

[NICE's guideline on cerebral palsy in under 25s, recommendation 1.1.1 and expert consensus]

Enhanced clinical and developmental follow-up

Enhanced clinical and developmental follow-up ensures that a child has their movement and development closely checked. This should happen at their routine appointments up to age 3 months. They should then have extra follow-up appointments to check for problems until they are 2 years old. However, these should be tailored to the needs of the child or young person. Follow-up should be provided by an expert who can draw on the following expertise from a multidisciplinary team:

- paediatric medicine
- nursing care
- physiotherapy
- occupational therapy
- speech and language therapy
- dietetics
- psychology.

[Adapted from [NICE's guideline on cerebral palsy in under 25s](#), recommendation 1.5.3 and expert opinion]

Quality statement 2: Referral for children with delayed motor milestones

Quality statement

Children with delayed motor milestones are referred to a child development service.

Rationale

The diagnosis of cerebral palsy is typically based on observations and parental reports on the attainment and quality of motor milestones. Referral to a child development service will enable early diagnosis of cerebral palsy, guide interventions, inform prognosis and let family members know what to expect.

Quality measures

Structure

Evidence of local arrangements to provide child development services for children with delayed motor milestones.

Data source: Local data collection, for example, service protocols.

Process

Proportion of children with delayed motor milestones who are referred to a child development service.

Numerator – the number in the denominator who are referred to a child development service.

Denominator – the number of children with delayed motor milestones.

Data source: Local data collection, such as the [Royal College of Paediatrics and Child Health personal child health record \('red book'\)](#).

Outcome

Number of children and young people with cerebral palsy who were diagnosed by age 2 years.

Data source: Local data collection.

What the quality statement means for different audiences

Service providers (such as primary care services) ensure that they provide healthcare professionals with training to enable them to identify delayed motor milestones in children.

Healthcare professionals (such as GPs, practice nurses and health visitors) are aware of motor milestones in children and refer children with delayed motor milestones to a child development service for multidisciplinary assessment.

Commissioners (such as clinical commissioning groups and local authorities) ensure that child development services are available to provide an assessment of motor milestones to help early diagnosis and intervention in children with delayed motor milestones.

Children with unusual signs that suggest possible cerebral palsy are referred to a specialist team at the local child development service for more checks to find out whether they have cerebral palsy. Examples of unusual signs are not sitting by 8 months, not walking by 18 months, or using one hand more than the other before 12 months.

Source guidance

[Cerebral palsy in under 25s: assessment and management. NICE guideline NG62 \(2017\), recommendation 1.3.6](#)

Definitions of terms used in this quality statement

Delayed motor milestones

The following are the most common delayed motor milestones in children with cerebral palsy:

- not sitting by 8 months (corrected for gestational age)
- not walking by 18 months (corrected for gestational age)
- early asymmetry of hand function (hand preference) before 1 year (corrected for gestational age).

[[NICE's guideline on cerebral palsy in under 25s, recommendation 1.3.5](#)]

Child development service

A service that offers multidisciplinary assessment for children and that:

- provides the following expertise, as appropriate, through a local network of care:
 - paediatric or adult medicine
 - nursing care
 - physiotherapy
 - occupational therapy
 - speech and language therapy
 - dietetics
 - psychology

- can enable access to other services within their local or regional network as appropriate, including:
 - paediatric or adult neurodisability, neurology, neurorehabilitation, respiratory, gastroenterology and surgical specialist care
 - orthopaedics
 - orthotics and rehabilitation services
 - social care
 - visual and hearing specialist services
 - teaching support for preschool and school-age children, including portage (home teaching services for preschool children).

[Adapted from [NICE's guideline on cerebral palsy in under 25s](#), recommendation 1.5.3]

Quality statement 3: Information for parents and carers of children and young people with cerebral palsy

Quality statement

Parents and carers of children and young people with cerebral palsy are given information about the diagnosis and management of cerebral palsy.

Rationale

Providing information is essential in enabling parents and carers to help children and young people with cerebral palsy to manage their condition and in reducing the chance of complications. It also helps to reduce the anxiety associated with a cerebral palsy diagnosis and improve satisfaction with the care process for the person diagnosed and their parents or carers. Parents should be given information from diagnosis and throughout the person's care.

Quality measures

Structure

Evidence of local arrangements to ensure that parents and carers of children and young people with cerebral palsy are provided with up-to-date information on the diagnosis and management of cerebral palsy that is tailored to their needs.

Data source: Local data collection, for example, service protocols.

Process

Proportion of parents and carers of children and young people with cerebral palsy who are given information about the diagnosis and management of cerebral palsy at the point of diagnosis.

Numerator – the number in the denominator whose parents or carers are given information about the diagnosis and management of cerebral palsy.

Denominator – the number of children and young people with cerebral palsy.

Data source: Local data collection, such as the child or young person's personal folder.

Outcome

Level of parent and carer satisfaction with information they are given about the diagnosis and management of cerebral palsy.

Data source: Local data collection based on feedback from parents and carers of children and young people with cerebral palsy.

What the quality statement means for different audiences

Service providers (such as child development services) ensure that systems are in place to provide up-to-date and tailored information about the diagnosis and management of cerebral palsy to the parents and carers of children and young people with cerebral palsy.

Healthcare professionals (such as paediatricians, nurses, physiotherapists, occupational therapists, ophthalmologists, speech and language therapists, dietitians and psychologists) provide information about the diagnosis and management of cerebral palsy to the parents and carers of children and young people with cerebral palsy.

Commissioners (such as clinical commissioning groups) ensure that services are in place to provide information on the diagnosis and management of cerebral palsy and associated comorbidities to the parents and carers of children and young people with cerebral palsy, and that the information is tailored to their individual needs and learning styles.

Parents and carers of children and young people children with cerebral palsy are given information about the child or young person's diagnosis, the treatment they will receive and other conditions associated with cerebral palsy.

Source guidance

Cerebral palsy in under 25s: assessment and management. NICE guideline NG62 (2017), recommendation 1.6.2

Definition of terms used in this quality statement

Information on diagnosis and management of cerebral palsy

The information provided should cover:

- diagnosis
- aetiology
- prognosis
- expected developmental progress
- comorbidities
- availability of specialist equipment
- resources available and access to financial advice, respite care, social care and other support for children and young people, and their parents, carers and siblings
- educational placement (including specialist preschool and early years settings)
- transition.

[NICE's guideline on cerebral palsy in under 25s, recommendation 1.6.2]

Equality and diversity considerations

Parents and carers of children and young people with cerebral palsy should be provided with information that they can easily read and understand themselves, or with support, so they can communicate effectively with health and social care services. The information should be in a format that suits their needs and preferences. It should be accessible to people who do not speak or read English, and should be culturally and age appropriate. Children and young people with cerebral palsy should have access to an interpreter or

advocate if needed.

For children and young people with cerebral palsy who have additional needs related to a disability, impairment or sensory loss, information should be provided as set out in [NHS England's accessible information standard](#).

Quality statement 4: Personal folders for children and young people with cerebral palsy

Quality statement

Children and young people with cerebral palsy have a personal folder to help them make decisions about how their condition is managed.

Rationale

A personal folder will hold information about the child or young person with cerebral palsy that can be shared with health, social care and education providers to ensure good communication. Having a personal folder can help children and young people with cerebral palsy, their families and carers to take control and make informed decisions about their lives and how their condition is managed. Children and young people should be involved in creating their own folder, which is tailored to their needs and evolves throughout the patient pathway. The personal folder should remain with the child or young person.

Quality measures

Structure

Evidence of a locally defined approach to the development of personal folders for children and young people with cerebral palsy to help them make decisions about how their condition is managed, and systems in place to make staff aware of the approach.

Data source: Local data collection, for example, service protocols.

Process

Proportion of children and young people with cerebral palsy who have a personal folder to help them make decisions about how their condition is managed.

Numerator – the number in the denominator who have a personal folder to help them make decisions about how their condition is managed.

Denominator – the number of children and young people with cerebral palsy.

Data source: Local data collection based on audits of patient care records.

Outcome

Levels of satisfaction of children and young people with cerebral palsy with control over care and daily life.

Data source: Local data collection based on feedback from children and young people with cerebral palsy.

What the quality statement means for different audiences

Service providers (such as health, social care and educational providers) ensure that systems are in place for children and young people with cerebral palsy to have a personal folder that can be shared with family members and carers, and used in health, social care and educational settings.

Health and social care practitioners help children and young people with cerebral palsy and their parents or carers to develop and update a personal folder to help them make decisions about how their condition is managed.

Commissioners (such as clinical commissioning groups) ensure that they commission services that support children and young people with cerebral palsy to be involved in developing a personal folder that is updated throughout the entire care pathway to help them to make decisions about how their condition is managed.

Children and young people with cerebral palsy have a personal file with information that is unique to them. Their care team helps them to put the information together and keep it up to date. The personal file can help children and young people make decisions about the care they would like to have. It can be in an electronic or paper format, and can be shared with everyone who supports the family, including friends, other family members, health

professionals, social workers and teachers.

Source guidance

Cerebral palsy in under 25s: assessment and management. NICE guideline NG62 (2017), recommendation 1.6.5

Definition of terms used in this quality statement

Personal folder

A personal folder is a file that contains information about the child or young person with cerebral palsy that can be shared with family members and friends, and used in health, social care and education. The file can be in an electronic format, or on paper, whichever is preferred by the child or young person and their family or carers. It could include:

- early history
- motor subtype and limb involvement
- functional abilities
- interventions
- medication
- comorbidities
- preferred methods of communication
- any specialist equipment that is used or needed
- care plans
- emergency contact details.

[NICE's guideline on cerebral palsy in under 25s, recommendation 1.6.5]

Equality and diversity considerations

Children and young people with cerebral palsy should be provided with information that they can easily read and understand themselves, or with support, so they can communicate effectively with health and social care services. Information should be in a format that suits their needs and preferences. It should be accessible to people who do not speak or read English, and should be culturally and age appropriate. Children and young people with cerebral palsy should have access to an interpreter or advocate if needed.

For children and young people with cerebral palsy who have additional needs related to a disability, impairment or sensory loss, information should be provided as set out in [NHS England's accessible information standard](#).

About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about [how NICE quality standards are developed](#) is available from the NICE website.

See our [webpage on quality standard advisory committees](#) for details of standing committee 1 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available from the [webpage for this quality standard](#).

This quality standard has been included in the [NICE Pathway on cerebral palsy in under 25s](#), which brings together everything we have said on a topic in an interactive flowchart.

NICE has produced a [quality standard service improvement template](#) to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Improving outcomes

This quality standard is expected to contribute to improvements in the following outcomes:

- health-related quality of life of children and young people with cerebral palsy
- functional independence of children and young people with cerebral palsy
- educational participation of children and young people with cerebral palsy
- wellbeing of parents and carers of children and young people with cerebral palsy.

It is also expected to support delivery of the following national frameworks:

- [Adult social care outcomes framework](#)
- [NHS outcomes framework](#)
- [Public health outcomes framework for England](#)
- [Quality framework for public health.](#)

Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource impact work for the source guidance. Organisations are encouraged to use the [resource impact statement for the NICE guideline on cerebral palsy in under 25s](#) to help estimate local costs.

Diversity, equality and language

During the development of this quality standard, equality issues were considered and [equality assessments for this quality standard](#) are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with

compliance with those duties.

ISBN: 978-1-4731-2545-2

Endorsing organisation

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- [Action Cerebral Palsy](#)
- [Royal College of General Practitioners \(RCGP\)](#)
- [Royal College of Nursing \(RCN\)](#)
- [Association of Paediatric Chartered Physiotherapists](#)
- [Royal College of Paediatrics and Child Health](#)